

# A Patient-centred approach to measuring quality in kidney care: PROMS and PREMS

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# **A Patient-centred approach to measuring quality in kidney care:**

## **PROMS and PREMS**

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## **Purpose of review**

Chronic kidney disease (CKD) is associated with symptoms that can significantly reduce the health-related quality of life (HRQOL) of patients. Patient-reported outcome and experience measures (PROMs and PREMs) may assist with the evaluation of HRQOL and quality of care from the patient perspective. This review focuses on evidence from recent studies exploring the role of PROMs and PREMs in the measurement of quality in CKD care.

## **Recent findings**

PROMs are increasingly used in CKD research as measures of clinical effectiveness, whilst the current use of PROMs in routine clinical settings and PREMs in all settings is more limited. Electronic PROMs may be sensitive enough to detect clinically relevant PRO changes. Patients on frequent shorter-hours daily haemodialysis may experience better HRQOL compared to those on conventional haemodialysis. PROM data may correlate significantly with clinical parameters. PREMs are being utilised by healthcare professionals to inform service improvements.

## **Summary**

PROMs and PREMs may facilitate the measurement of quality in renal care and aid the tailoring of care to individual patients. PROMs may have a potential role as prognostic markers.

## **Keywords**

patient-reported outcome measures, PROMs, patient-reported experience measures, PREMs, chronic kidney disease, quality of life, quality of care

## Introduction

Chronic kidney disease (CKD) affects up to 14% of the global population [1\*, 2]. In many regions of the world, governments and individuals struggle to meet the costs of treating CKD and its complications [3\*]. Although recent reviews reported a plateauing of the prevalence of CKD since 2000's [4\*, 5], CKD is and will remain a major global public health problem and the focus of detailed attention by healthcare professionals and policy makers [3\*].

Patients with CKD often experience a high symptom burden which negatively impacts on their health-related quality of life (HRQOL) [6, 7]. Clinician-reported outcomes such as mortality rates, stage of kidney disease and survival rates are established indicators of health [8]. However, it is increasingly acknowledged that clinician-reported outcomes do not adequately capture patients' HRQOL and underestimate their symptom burden [8, 9]. This may lead to a conflict of priorities between patients and clinicians, as aspects of HRQOL and symptoms that matter to patients may not be prioritised by the clinical team. HRQOL and/or symptoms can be measured from a patient perspective, without interpretation by anyone else, using self-administered, validated questionnaires also known as patient-reported outcome measures (PROMs) [10]. Therefore, the use of PROMs may complement clinician-reported outcomes by eliciting actionable information about patient HRQOL and/or symptoms and possibly assisting with the alignment of patient and clinician care priorities [11\*\*].

Patient experience of care is now formally recognised as a crucial element of healthcare quality alongside patient safety and clinical effectiveness [12, 13] and its measurement can facilitate a patient-centred approach to evaluating healthcare

quality [14\*]. Patient experience of care may be objectively measured using patient-reported experience measures (PREMs). Figure 1 shows the inter-relationships between elements of healthcare quality and measures of patient-reported outcomes and experience.

In this review, we present an overview of the use of PROMs/PREMs, and examine evidence from recent studies exploring the role of PROMs/PREMs in the measurement of quality of care specifically in CKD. We also summarize recent evidence of the use of PROMs/PREMs in other health conditions. Finally, we highlight key challenges and technological developments that may influence the use of PROMs and PREMs in future.

## Overview of PROMs and PREMs

PROMs are increasingly used in research settings such as clinical trials, cohort studies and prognostic modelling, to appraise the effectiveness and long-term safety of treatments from patients' perspective [10, 15\*]. A quick search of 'patient-reported outcome measures' on PubMed for the last 10 years, using the 'clinical trials' filter, yielded 1,878 entries – almost twice the number obtained for the previous decade; demonstrating the increasing use of these measures in clinical trials. On the other hand, the use of PROMs in routine clinical practice, and PREMs in all settings, is limited.

In clinical practice, aggregated PROM data is commonly used to audit and benchmark the performance of hospitals [16]. Since 2009, NHS England has used PROMs to assess the quality of care delivered by NHS providers and quantify post-operative health gains from the patient perspective for surgical procedures comprising: total hip replacement, total knee replacement, varicose vein procedures, and groin hernia repairs [16].

PROMs can also be used at an individual patient level in clinical practice to help to ensure that important aspects of health, that matter to patients, are brought to the attention of clinicians [14\*]. Evidence suggests that this contemporary application of PROMs may improve patient-clinician communication [17], and inform and promote shared decision making [17-19].

PREMs are designed to inquire about specific details of care and the actual occurrence of specific processes and/or events [20] rather than satisfaction with care. By adopting this approach, bias and subjectivity that arise from patients' expectations may be minimised [21, 22].

PREMs assess a variety of domains including co-ordination of care, respect for patient preferences, and provision of medical information. Hospitals rated higher by patient experience questionnaires also perform better on clinical metrics [20, 23]. However, evidence of generalisation of use is very limited; this is a shortfall as PREMs can benchmark hospital performance and identify areas of service provision that require improvement [20]. PREM data may also be used to calculate incentive payments and produce reports which are made publicly available to enable patients make informed choices about their care [24].



## **PROMs and PREMs in CKD**

Patients with CKD require long term care, the quality of which may have a significant impact on their HRQOL. PROMs/PREMs provide patients with an opportunity to describe the impact of disease and treatment on HRQOL, symptoms and the quality of care they receive from their perspective.

### **Selection of measures: evidence from systematic reviews**

There are numerous PROMs/PREMs available [25]. To ensure that appropriate measures are selected, it is vital that the purpose of measurement, the target population, the psychometric evidence supporting the measures under consideration, and the setting are carefully considered [26]. Systematic reviews of PROMs/PREMs may provide psychometric evidence which may facilitate the selection process.

A systematic review recently conducted at the Centre for Patient-Reported Outcomes Research (CPROR), University of Birmingham, found evidence to support the use of the Kidney Disease Quality of Life-36 (KDQOL-36) for pre-dialysis patients; the KDQOL-36 & KDQOL-SF for dialysis patients; and the End Stage Renal Disease-Symptom Checklist Transplantation Module (ESRD-SCLTM) for transplant patients on immunotherapy [27\*]. The Integrated Patient Outcome Scale-Renal (IPOS-Renal) is a new renal-specific tool that is currently being piloted by the UK Renal Registry. Its validation is on-going [28]. See Table 1 for a description of all the PROMs referred to in this review.

A recent review by Beattie et al. [20] found evidence to support the use of a number of generic PREMs and recommended the use of the Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) for purposes relating to research or financial remuneration; the Quality from the Patients' Perspective Shortened (QPPS) to assess the effectiveness of quality improvement at a local level; and the Quality improvement in low-income settings (I-PAHC) for low-income settings [20]. The Care Experience Feedback Improvement Tool (CEFIT) is a new measure intended for quality improvement based on patient experience [36]. The majority of PREMs identified by Beattie et al. were designed for use after discharge from hospital and varied widely in terms of purpose, the domains assessed and timing of administration making it difficult to recommend any for use in CKD. There is therefore a need to validate generic PREM tools in renal disease-specific settings or develop new tools that may be more relevant.

The validated renal-specific PREMs available are limited to dialysis and comprise:

1. CAPHS In-Center Haemodialysis Survey [37, 38]
2. Consumer Quality Index for chronic dialysis [39, 40]

The validation of the UK Renal Registry (UKRR) National PREM survey was recently completed by the research team at University of Hertfordshire. Early reports of its psychometric properties are encouraging and the full report is due to be published shortly [31]. See Table 2 for a description of all the PREMs referred to in this review.

## **PROMs in CKD clinical trials and research**

A clinical trial by Garg et al. used PROMs to evaluate the differences in HRQOL in patients on different haemodialysis treatments. They found that patients who receive frequent shorter hours daily haemodialysis reported better HRQOL compared to those on conventional haemodialysis [45\*].

The Dialysis Outcomes and Practice Patterns Study (DOPPS) administers the KDQOL-36 to its cohort of haemodialysis patients annually. The study has reported associations between PROMs and clinical outcomes including mortality rates, even after adjusting for potential confounders. The researchers concluded that PROMs could be used as prognostic markers [46\*].

## **PROMs in CKD routine clinical practice**

Recent international developments suggest that the use of ePROMs may help tailor care to individual patient needs and improve patient outcomes. Pittman et al. [47\*\*] recently demonstrated that it is not only feasible to collect electronic PROMs (ePROMs) but that ePROMs could be sensitive enough to detect clinically relevant changes in PROs in both short and longer term. They reported significant correlations between PROM data and clinical parameters, such as haemoglobin and eGFR, at levels of change that have not been previously described [47\*\*]. They also suggested that ePROMs may be of use in pre-dialysis or dialysis patients by providing “early warning” prompts for issues such as fluid status and failure to thrive [47\*\*].

A generic ePROM system, AmbuFlex, was developed in Denmark for the collection of PRO data to support symptom assessment and clinical decision making in outpatient settings [48\*]. By 2015, a total of 13,135 outpatients from 15 clinics were individually referred for remote ePROM follow-up and up to 18,912 questionnaires were collected [48\*]. An automated algorithm analyses PRO data collected for nine diagnostic groups, including renal failure, and decides whether patients require an outpatient consultation or not [48\*]. The completion of an ePROM led to an overall decrease of up to 50% in hospital visits for the follow-up cases analysed. This could potentially lead to more efficient use of resources by freeing up appointment slots for patients who need to be seen in clinic [48\*].

A recent pilot study at two outpatient dialysis clinics in Canada, using electronic versions of the KDQOL-36 and the Edmonton Symptom Assessment Scale (ESAS), confirmed that the collection of ePROMs may be feasible and acceptable to patients in routine practice [49, 50]. Whilst emerging evidence of use of ePROM systems in a US oncology setting suggests that real-time monitoring and clinical response to ePROM data may reduce hospitalizations, improve HRQOL and even improve survival [11\*\*]. CPROR are currently undertaking feasibility and pilot work of a similar ePROM system.

## **PROMs and PREMs in renal registries**

There are up to 144 renal registries worldwide [51] but their collection and use of PROM/PREM data is very limited. A review by Breckenridge et al. [40] reported that in Europe, only registries in Austria and France collected PROMs/PREMs [40]. In 2015, the UKRR, in partnership with NHS England, commenced the 'Valuing

Individuals: Transforming Participation in Chronic Kidney Disease' (TP-CKD) programme to assess the feasibility and sustainability of routine collection of PROMs and PREMs from patients with CKD [44]. The UKRR, in conjunction with the British Kidney Patient Association (BKPA), also developed a national strategy for an annual PREM survey to facilitate the benchmarking of kidney patient experience and inform service improvement for individual renal teams [52].

## **Challenges for PROMs and PREMs in CKD**

While there are clear benefits of using PROMs/PREMs, there are also challenges associated with their implementation. While the implementation of PROMs/PREMs in clinical trials has been extensive, in clinical practice it has been relatively slow [53] despite the significant methodological advances in instrument development and psychometric testing. Specific areas that require attention include:

### **Implementation strategy**

A number of guides and frameworks have been developed [53-56\*] but it is unclear whether these have made any impact on the implementation of PROMs/PREMs in clinical practice or trials [57\*]. Challenges with the NHS PROMs initiative illustrate the importance of introducing PROMs in a staged manner, and piloting the utility of a PROM in a defined clinical setting before generalising into mainstream clinical practice [57\*].

The successful implementation of PROMs/PREMs requires a robust implementation strategy backed by strong and effective leadership [58]. Appropriate infrastructure relating to technological capability and data security need to be sorted out before the process is commenced [49, 50]. PROMs/PREMs collection and utilisation need to be integrated with existing clinical pathways and data collection methods to facilitate their adoption by clinicians [59-61]. There is a need for clear guidelines on how to effectively aggregate and incorporate patient-level PROM data into routine care in CKD [62, 63].

For clinical trials, implementation strategies are required to ensure uniform administration of PROMs/PREMs across trial sites and address the current tendency

for data collected with these measures to be compromised by high levels of missing data (a potential source of bias) [64].

## **Clinician scepticism**

Although the use of PROMs in clinical trials has increased significantly in the past few years [65], clinician doubts about the benefits of PROMs and PREMs in clinical practice have persisted and remain an important challenge to the implementation of PROMs/PREMs. A taskforce was recently convened by CPROR and Birmingham Health Partners to assess the evidence and reflect on the UK National PROMs programme. One of its conclusions was that clinicians who traditionally rely on quantitative clinical data to inform clinical decisions are still unconvinced by the evidence supporting the use of PROMs to inform service change [57\*]. Rotenstein et al. [66] have stressed the importance of clinician buy-in to ensure the success of any implementation plan [66].

## **Interpretation and presentation of data**

For PROMs/PREMs data to be of any value, it has to be accurately interpreted and translated into actionable information that can be used to inform and drive quality improvements within the healthcare system. After interpreting PROMs/PREMs data, the findings have to be presented in a format that will make sense to stakeholders and decision makers [63, 66]. It has been suggested that one of the reasons the NHS PROMs programme has had no appreciable impact to date may be due to the poor presentation quality of data [62]. Different approaches might be required when presenting PROM data to patients and clinicians [67]. A review by Bantug et al. [68\*] reported that patients prefer simple line graphs and interpret them with the highest accuracy. Clinicians were found to prefer similar graphs but valued greater detail

[68\*, 69]. There is an urgent need for more work needs to be done to establish standards for PROM data interpretation and presentation [67].



## **The future of PROMs and PREMs**

At present, the most common method of collecting PROM/PREM data is by the administration of paper-based questionnaires. However, this is changing rapidly as access to the internet improves and more people embrace the use of technological innovations such as smartphones, tablet devices and mobile phone applications [49, 70]. The ePROM system researchers at CPROR and University Hospitals Birmingham NHS Foundation Trust are currently working on may assist with the remote monitoring of symptom deterioration between scheduled clinic appointments and provide clinicians the opportunity to intervene promptly. It may also encourage patients to become more engaged with their care and potentially facilitate shared decision making between patients and clinicians, an integral principle of patient-centred care [14\*].

Computer adaptive testing (CAT) is an algorithm-based method of PROM administration whereby the most relevant items (questions) from an item bank are automatically selected and administered sequentially, based on a respondent's prior responses with the aim of maximizing the information obtained about the respondent [71\*]. Using a CAT simulation of the World Health Organization Quality of Life (WHOQOL)-100 questionnaire, Gibbons et al. [71\*] recently demonstrated that electronic item banks could provide accurate measurements that are significantly shorter and often more reliable than paper-based versions [71\*]. The significant progress in the development of open-source platforms mean that it is possible for researchers and clinicians to deploy cloud-based CATs directly to patients via the Internet and mobile phone applications [72].

Current technological innovations may also assist with the integration of PROM data with other routinely collected electronic health data such as laboratory test results. This integrated data also referred to as 'Big Data' has the potential to facilitate the delivery of high quality care that is "*personal and tailored*" to individual patients, development of diagnostic algorithms, and enhanced clinical audit [73, 74].

## **Conclusion**

The drive for improvement in quality of renal care requires the adoption of a patient-centred approach to the provision of renal care and the measurement of its quality for significant progress to be achieved. Health providers need to design and properly implement robust strategies, which put the patient at the heart of service provision. This requires effective leadership and significant cultural and organisational changes.

The use of PREMs and PROMs may facilitate this process by giving patients the avenue to provide actionable information about their health and encouraging shared decision making between patients and their healthcare providers/clinicians. Recent advances in technology could lead to PROMs/PREMs playing a significant role in transforming health care delivery in future.

## Key points

- PROMs and PREMs have applications in research; clinical trials and routine clinical practice, and may facilitate a patient-centred approach to renal care.
- PROMs may be used to evaluate quality of life from a patient perspective.
- PROMs could potentially complement clinician-reported outcomes in the clinical management of CKD patients.
- PREMs may be used to evaluate quality of care from a patient perspective.
- PREMs may facilitate quality improvement in renal care services.

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## **Conflicts of interest**

There are no conflicts of interest.

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### **Figure titles and legends**

Figure 1. Inter-relationships between PROMs, PREMs, elements of high-quality care and Patient-centred care (P.C.C).

